

Productivity Commission Inquiry into Disabilities

My son was diagnosed with mild Asperger's Syndrome when he was 12 years old however this came after years of heartache and searching for answers.

Our lives changed the moment my son stepped through the Kindergarten doors. I truly believed that he would excel at school because he was such an intelligent and loving boy. His teachers reaffirmed my beliefs about his intelligence but told a very different story about his social abilities. They told me he was socially awkward, disruptive in class, displayed 'inappropriate' behaviour in the play ground and angers easily. These reports didn't make sense, in fact were the opposite of what I believed my child to be. I put it down to a rough start thinking things would work out over time.

One afternoon he told me that he was being teased, particularly during sports because he didn't run like the other children and said odd things like how people could leap over the long jump pit if gravity didn't exist. His hurt became my hurt and it seemed as though I was in constant contact with the school requesting that they do something to protect him from the teasing. Although they were sympathetic, we fell into the too hard basket as they simply couldn't make other children like him.

When he was in second grade, his teacher told me that he was talking about committing suicide. A milestone I will never forget. Although comfortable being alone he couldn't bare the constant taunting and rejection of others. The school scheduled counselling sessions for me. My child needed to learn appropriate behaviours and build his resilience. In one session, the counsellor suggested that he may have ADHD and handed me a book.

Although I majored in psychology, it never dawned on me that my child's development was impeded. He didn't display any anti-social behaviours at home or when he visited family but he did seem to be the odd one out playing with other children so I started to read the book. Some of the behaviours were similar however I wasn't convinced.

In grade 4, my son was offered a position with in a private all boys school which I eagerly took in the hope of a fresh start. Within the first year, the bullying and teasing started again but with a great deal more ferocity. He developed a vocal tic, became increasingly disorganised and found the computer to be his only sanctuary. When he asked for help from his teacher, he was told not to be such a pain. The swimming and sports carnivals brought humiliation and the school camp took pack mentality to new heights. Again my requests for action to protect my son fell on deaf ears and I was clearly warned not to question the school's duty of care.

My son started to self harm and again threatened suicide. I finally admitted that I couldn't do this on my own any more and sought professional help. I called the Child and Adolescent Mental Health Services Triage but was deemed ineligible after answering a questionnaire over the phone because

my son was not severe enough. After talking to friends and doing my own research, I decided the best help was a multi-disciplinary clinic in Sydney. The clinic offers a one day intensive including an assessment by a renowned paediatrician and a range of psychometric tests but I needed a referral first.

I went to see my son's GP. He questioned the need for such a service. After putting my case forward, he told me that he did not believe in fad developmental disorders and stated that there was nothing wrong with my son, rather I had a parenting disorder and needed to re-connect with my child. However, he gave me the referral I was after, albeit reluctantly.

Soon after, we attended the clinic. Following an initial consultation with the paediatrician, my son was tested for physical, emotional and psychological difficulties. One test used an EEG to monitor brain activity whilst processing information. This test found my son had the markers of ADHD. Ritalin was administered and during a retest, my son showed decreased levels of activity. He was subsequently diagnosed with ADHD and prescribed regular medication. It is worth noting, that the clinic lists the conditions they diagnose.

Two months of medication provided no relief. In fact, things progressively became worse. So, I made a decision to stop medicating him. One afternoon, my son was waiting for his bus when another boy threw him to the ground, bent him over and pretended to rape him, he yelled obscenities and was cheered on by the crowd. This was the final straw. I called the Catholic Education Office, the school was outside of their jurisdiction and they were clearly not interested in the case.

My son had been on a waiting list with another private school for several years, so I called the Principal to request a meeting. I told him of my desperation and through tearful eyes begged for his compassion. I was convinced he would end his life if this continued. Months later, he was offered a position and he started immediately.

This was to be our 'Saving Grace', however, the usual problems started and the school contacted me to discuss. But this meeting was of a very different nature. They had carefully observed my son and suspected that he was showing signs of Asperger's Syndrome. Coincidentally, through my own research, I suspected the same. They suggested that I consider seeing a developmental psychologist and reassured me that the school environment would be supportive and nurturing. They hold a firm belief that these children enrich the experience of other students and provides them with an acceptance of all people in our society.

Funding

If my son was diagnosed before the closing date for funding submission that year, the school would receive funding the following year to provide him with additional support. However the process took many months to finalise. A GP examined him physically and ran a blood test. The GP referred us to a paediatrician who then referred us to the recommended psychologist. The psychological assessment considered both home and school environments

through observations, parent/teacher interviews and questionnaires. He was diagnosed with Asperger's Syndrome. Even though I believe this to be correct, I started to grieve. A fear of always being on the outskirts of society swept over me. My expectations, hopes and dreams as a parent needed to readjust to this reality.

The diagnosis was provided to the school and they applied for funding in the following year as the deadline has passed but they offered assistance regardless. The school has offered supported job experience, a job ready course, a social skills course and ASD group sessions for parents. When they applied for funding, they contacted me to agree on his level of needs. I don't know the amount they receive for him.

In addition, I had an occupational therapist visit our home, we have received advice from a dietician, my Mum organised a personal trainer to assist with his gait and we have had many visits with psychologists. The benefits of these activities are varied.

The best treatment for my son has been environmental. Finding a school that demands understanding and acceptance in all students, has been of the greatest benefit. Although healing has occurred some experiences are irreversible and those precious formative years can never be reclaimed. My biggest challenge has been to protect him from negative external influences that so easily took away his self worth and will to live.

Ignorance still exists where help and protection should be present. I found this in schools with old boy thinking and in an uninformed GP. For us, there was no clear pathway to help; the track was barely visible and we never really knew where we were meant to be. As recently demonstrated, social commentators still advocate separatism and labelling. In addition to changes to service improvements and economic support, I believe a fundamental shift in social attitudes, particularly in our young, will reduce the level of disability (and suicide rate).

Name withheld
ACT

Attachments:

Student Centred Appraisal of Need – ACT Government – Education & Training

www.det.act.gov.au/publications_and_policies/publications_a-z/?a=20127